

The Danish HNPCC-System – Biomedical support to individual health care in here-ditary colon cancer families

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The Danish HNPCC-register (<http://www.hnpcc.dk/>) is a national database financed within the National Public Healthcare System. Epidemiological and genomic data of all families with Hereditary Colorectal Cancer (HNPCC) is included in the register to improve prognosis by identifying family members at risk and initiate and establish screening. Diagnostic data are generated in different departments and laboratories all over the country and collected over several decades in the register. Until recently paper-based reports were sent to the register and typed into the database. In the EC co-funded – INFOBIOMED network of excellence (www.infobiomed.org), The Danish HNPCC-register was used as model for electronic exchange of clinical data between diagnosing/treating departments and the HNPCC-register. The aim was to prevent cancer by optimizing organization of screening with digitization of data transport and facilitation of combining genotype-phenotype information. IT-tools, sufficiently usable and generic to be implemented in other countries and for other oncogenetic diseases, were developed.

Medical data are very heterogeneous, wherefore focuses were on integration, elaboration and dissemination of classification systems and communication standards. Several gaps identified in the project: Lack of standards for data-exchange, lack of local databases suitable for direct communication, reporting being time-consuming and dependent on interest and feedback. Till now the HNPCC-system has been implemented in 18 departments and future aim is to include all departments in the country taking part in treating families with hereditary colorectal cancer. Although there is room for improvements a major benefit of implementation is an increase of 192% of surgical reports to the register.

Biography

Inge Bernstein is a colorectal surgeon and has completed her Ph.D from Copenhagen University and Master of Health Management from Copenhagen Business School. She is director of The Danish HNPCC-register, a National register including epidemiological and genomic data on all Danish families with Hereditary Non Polyposis Colorectal Cancer. The aim is to improve prognosis by identifying at-risk family members, establish screening and evaluate the outcome. She has published more than 60 papers in reputed journals and is serving as an editorial board member of the Danish Colorectal Cancer Group and the InSiGHT (International Society of Gastrointestinal Hereditary Tumours).

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